

PULMONARY FIBROSIS

GENERAL INFORMATION:

What is it?

- Pulmonary fibrosis (puhl-mo-nary) is also called "interstitial (in-ter-stih-shel) pulmonary fibrosis," "interstitial lung disease," or "ILD." It is a general name for a large group of about 180 lung diseases. They are serious diseases that effect the tissues of the lungs. People usually get ILD between 40 to 70 years of age.
- ILD can be a very mild or very bad disease. How your ILD progresses depends on which type you have. There is no cure for ILD, but its symptoms often may be controlled. ILD may get worse and can cause death, even with treatment.

Causes:

- What causes ILD in most people it is not known. Some scientists think that it may be genetic. A genetic disease is one that you are born with and that you inherit from your family. The following are some of the things that may cause ILD.
 - Working around dusts like "asbestos," "silica," or metal.
 - Radiation and some medicines.
 - Bad allergies to molds or other things floating in the air.
 - Other diseases like arthritis or systemic sclerosis.
 - Lung or other infections.
 - Smoking or being around smokers is being studied.
- Inflammation (redness and swelling) in the lungs is common in all the types of ILD. The airways into your lungs have or tiny little sacs at the ends. With these diseases, the walls of the blood vessels, airways, alveoli (owl-vee-o-li) or air sacs become swollen. If the swelling continues the surrounding tissues become "fibrotic" or scarred over time. This means they becomes thick and stiff. When this happens, it is very hard to breathe. Remember normal lungs are soft and move easily as you breathe air in and out.

Signs and Symptoms:

You may have one or more of the following symptoms.

- Dry cough.
- Fingertips and nails become large and bulb-like (clubbing).
- Heart failure with swelling of the legs.
- Lasting tiredness.
- Trouble breathing, especially with exercise.
- Weight loss.

Care: There is no cure for ILD. The lung scarring or damage caused by ILD cannot be reversed but the symptoms can be treated. Caregivers will work with you to help you keep a good quality of life for as long as possible. At first, you may probably be seen in a clinic or caregiver's office. But, at times, you might need to go into the hospital for tests and treatment. You may need to see your caregiver 1 to 4 times a month. Ask your caregiver for information about ILD to help you understand the different problems and treatments.

- Your caregiver may suggest one or more of the following ILD tests or treatments. This will help to further identify your specific lung disease.
 - Physical exam.
 - Blood tests.
 - Bronchoalveolar lavage (BAL).
 - Bronchoscopy.
 - CT scan.
 - Pulmonary function tests (PFTs).
 - Surgical lung biopsy by thoracoscopy or thoracotomy.
 - X-rays.
- If ILD is found early enough, your caregiver may be able treat you with medication to slow down the process. You may have to take medicines for the rest of your life. Some of the medicines have side effects. Caregivers will tell you about these possible side effects. Sometimes medicines may not work at all and the damage will continue. You may have to learn special ways to breathe better and may need to wear oxygen.
- Transplant surgery might be suggested for some types of ILD. This means caregivers replace your lungs or your heart and lungs with ones taken from someone after they die.
- Physical or emotional stress may cause a flare up of symptoms. You may need to go into the hospital for more care.

Coping: ILD is a life-changing disease for you and your family. Accepting that you have ILD is hard. You and those close to you may feel angry, depressed, or frightened. These are normal feelings. Talk to your caregivers, family, or friends about your feelings. You may also want to join a support group. This is a group of people who have lung problems just like yours. Call or write the following support group for more information about ILD.

- American Lung Association
National Office
1740 Broadway
New York, NY 10019-4374
Phone: 1-800-586-4872
Web Address: <http://www.lungusa.org>

- Pulmonary Fibrosis Association
P.O. Box 75004
Seattle, WA 98125-0004
Phone: 1-206-417-0949

Web Address: <http://www.pulmonaryfibrosisassn.com>

CARE AGREEMENT:

You have the right to help plan your care. To help with this plan, you must learn about your health condition and how it may be treated. You can then discuss treatment options with your caregivers. Work with them to decide what care may be used to treat you. You always have the right to refuse treatment.

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